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ABSTRACT

This document examines the 10 essential attributes of primary health care contained in the U.S. Maternal and Child Health Bureau's definition of primary care. Primary care for children and adolescents is personal health care delivered in the context of family, culture, and community; the range of services meets all but the most uncommon health needs of the individuals and families being served. Primary care includes first contact care, and is continuous, coordinated, comprehensive, community oriented, family centered, accessible, culturally competent, developmentally appropriate, and accountable. Research focusing on the benefits of each of these attributes is discussed. It is argued that the health of children will greatly improve if every child has a primary care provider who provides care that is characterized by all 10 attributes. Contains 61 references. (MDM)

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ANALYSIS OF THE CONCEPT OF PRIMARY CARE FOR CHILDREN AND ADOLESCENTS

A Policy Research Brief

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ANALYSIS OF THE CONCEPT OF PRIMARY CARE FOR CHILDREN AND ADOLESCENTS

A Policy Research Brief

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Analysis of the Concept of Primary Care for Children and Adolescents
A Policy Research Brief

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The **Child and Adolescent Health Policy Center (CAHPC) at the Johns Hopkins University** was established in 1991 by the federal Maternal and Child Health Bureau as one of two Centers to address new challenges found in amendments to Title V of the Social Security Act (MCH Services Block Grant) enacted in the Omnibus Budget Reconciliation Act (OBRA) of 1989. The purpose of the Center is to draw upon the science base of the university setting to help identify and solve key MCH policy issues regarding the development and implementation of comprehensive, community-based systems of health care services for children and adolescents. Projects are conducted to provide information and analytical tools useful to both the federal MCH Bureau and the State Title V Programs as they seek to meet the spirit, intent and content of the Title V legislation and the challenges of addressing the unique needs of MCH populations and programs in health care reform.

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INTRODUCTION

The Omnibus Budget Reconciliation Act (OBRA) of 1989 contained a number of amendments to Title V of the Social Security Act. These amendments redefined the program's mission in order to improve the health of all mothers and children (Public Law 101-239), in part by providing preventive and primary care services to low income children through the development (in each state) of a "statewide network of comprehensive, community-based health care systems [to] serve women of reproductive age, infants, children, adolescents, and children with special health care needs." These systems of care are to assure family-centered, culturally sensitive, and coordinated services for these populations (DHHS, 1990).

To help state maternal and child health (MCH) personnel begin to develop such systems, the federal Maternal and Child Health Bureau (MCHB) in collaboration with the Johns Hopkins Child and Adolescent Health Policy Center[1] and others have developed a definition of primary care for issuance by the MCHB. The purpose of this paper is to expand on the concepts contained in this definition in order to help state MCH personnel and others working in this area better understand what constitutes primary care and the importance of each attribute. A second objective of this paper is to review the currently available scientific evidence concerning the significance of each attribute specified in the definition of primary care.

While the definition of primary care contains some attributes (see below) that can be applied to system, provider, and individual levels, this paper focuses on the attributes of care from the perspective of the health care provider or facility.

This paper is divided into four sections. After the Introduction follows the definition of primary care as issued by the MCHB (1994). Then follows a section containing the analysis of each attribute[2] contained in the definition of primary care. This analysis first expands on the concepts supporting the defined attribute, then reviews the available literature to provide evidence concerning the benefit of the attribute, and finally, discusses the main issues that remain with respect to the attribute. The final section of the paper contains the authors' concluding comment.

DEFINITION OF PRIMARY CARE[3]

Primary care for children and adolescents is personal health care delivered in the context of family, culture and community whose range of services meets all but the most uncommon health needs of the individuals and families being served.

Primary care is the integration of services that promote and preserve health; prevent disease, injury and dysfunction; and provide a regular source of care for acute and chronic illnesses and disabilities. Primary care serves as the usual entry point into the larger health services system and takes responsibility for assuring the coordination of health services with other human services. The primary care provider incorporates community needs, risks, strengths, resources, and cultures into clinical practice. The primary care provider shares with the family an ongoing responsibility for health care.

In both the manner of its organization and the methods of its delivery, effective primary care for children and adolescents, including children with special health needs, incorporates and manifests certain essential attributes. These include:

- First contact
- Continuous[4]
- Coordinated
- Comprehensive
- Community[5] oriented
- Family[6] centered
- Accessible
- Culturally competent
- Developmentally appropriate
- Accountable

The basic assumption underlying the definition of primary care is that each child should have a primary care provider who provides care consistent with these attributes.

ANALYSIS OF ATTRIBUTES OF CARE

First Contact Care

Concept: The primary care provider provides 'first contact' care, which means that s/he is the first person contacted when a health or medical need arises. As such, the primary care provider serves as the usual entry point into the health care system. Where the primary care provider does not provide the first actual contact with the health care system, as in the case of emergencies or dental needs or perhaps even some specialty needs, it is by clearly defined policy rather than in response to any individual situation.

The primary care provider serves as a facilitator, directing patients to the appropriate care. While the notion of "gatekeeper", often associated with HMO practices, may conjure up visions of a provider trying to reduce costs by discouraging use of health care services, this is not the role intended for the primary care provider. Rather, the primary care provider guides patients to the most appropriate source of care at the appropriate time.

Having a primary care provider serve as the point of first contact serves two main functions. First, the patient benefits from obtaining care from the most appropriate source of care; second, to the extent that the gatekeeper either provides care him/herself or refers the patient to non-specialist providers, this practice is likely to result in lower costs of treatment, because specialist care is more expensive (Starfield, 1992).

Evidence of Benefits: The benefits of first contact care have been summarized by Starfield (1992). They include fewer visits to specialists, fewer emergency room visits, and lower hospitalization rates.

Discussion: Requiring all children to have a primary care provider who acts as the point of first contact is not without problems. First, implementing such a requirement may be difficult because of opposition from physician specialty groups who stand to lose income from such a requirement. Second, if there is a financial stake in restricting referrals to specialists, as is often the case in health maintenance organizations (HMOs), this could lead to inappropriate restriction on access to care (Starfield, 1992). Third, the implied lack of freedom of choice of providers is likely to meet with opposition from consumers who traditionally have possessed unrestricted choice of providers. However, consumers usually are permitted to choose their primary care provider from a panel of providers and may be allowed to change primary care providers periodically.

Continuous Care

Concept: Continuous care refers to the longitudinal use of a regular source of care over time, regardless of the presence or absence of disease or injury. The focus here is on the creation of a "health care home" recognized by both the patient and the provider. The health care home may be a single provider, a group of providers, or a facility; in the latter two cases care must be taken to coordinate the services received over time and to ensure that the patient establishes a relationship with the various providers. Regardless of the particular type of health care home, it is important that a unified record be kept at this site to document all health care provided over time.

Continuous care over time is intended to help the provider and the patient build a long-term relationship in order to foster trust in the provider on part of the patient, and a knowledge of the patient on part of the provider. Trust is important because a patient is likely to seek needed medical care earlier if s/he trusts the provider. Furthermore, compliance is likely to be increased if the patient trusts that the treatment prescribed by the provider is likely to be beneficial.

Knowledge of the patient and his/her family circumstances is beneficial to the provider because it allows him/her to better evaluate the symptoms presented by the patient. Symptoms can derive from a variety of underlying problems. Knowing the patient allows the provider to reduce the number of possibilities of causation and thus increases the chance of appropriately caring for the patient in a cost-effective manner. Furthermore, when a provider sees a patient over an extended period of time, s/he is more likely to discover health problems at a stage where they can be more easily treated and hence potentially reduce the cost of treating the patient (Starfield, 1992).

Evidence of Benefits: The demonstrated benefits of continuous care have been summarized by Starfield (1992). They include: better prenatal care, better appointment-keeping, better compliance with prescribed medication, better recognition of patients' needs, and lower cost of care. Continuous care over time is an advantage not only in cases of illness, but also in encouraging patients to seek preventive services.

Discussion: There is little doubt that having a health care home and receiving continuous care over time is beneficial to children and adolescents from a health perspective as well as to society from a cost perspective. Issues remain, however, about how to implement the concept. Is it better to have a provider or a group of providers as a health care home or is a facility enough? The current literature, while finding evidence of the benefit of both, has little to say on the relative merits of the two different types.

Coordinated Care

Concept: Coordinated care is the linking of health care events and services so that the patient receives appropriate care for all his/her health problems, physical as well as mental. The essence of coordination is "the availability of information about prior problems and services and the recognition of that information as it bears on needs for current care" (Starfield, 1992, p. 71). Problems often arise when a patient has a number of health care problems that must be treated jointly in order to provide appropriate care for the patient. The lack of coordination may result not only in failure to improve patient health, but also in duplication of medical tests and procedures, thereby increasing the cost of care. In some cases, lack of coordination may actually result in detrimental health outcomes, if the treatment for one health problem exacerbates another.

The primary care provider is responsible for transferring information from one health care event to the next, and for participating in the linking of treatment plans. Coordination can be facilitated through continuity of provider or information systems, including medical records. In practice, continuity is all too frequently broken because of visits to sites other than the primary care provider.

Medical records are commonly used to transfer information from one health care event to the next. However, the effectiveness of medical records is dependent on the information recorded and the accessibility of the records to health care personnel.

Mechanisms to facilitate coordination include a problem list contained in the medical record, computerized summaries of each patient encounter and problem(s), and computerized profiles of drug use and sensitivities.

Evidence of Benefits: The benefits of coordination and the usefulness of enhancing continuity by improvements in medical records have been summarized by Starfield (1992). For example, problem lists enhance recognition of information about patients, as does computerized feedback of certain types of information. Better coordination is also associated with better implementation of referrals and with better compliance.

Discussion: There is little doubt that coordination of care is an important attribute of primary care. However, evidence suggests that medical records and communication between providers are often inadequate. While mechanisms exist to improve coordination across providers and health care events, these are neither perfect nor agreed upon. The major challenge that remains in the coordination of care is to decide what information should be found in the medical record, what information must always be communicated to and from specialists and other providers (and over time), how to implement (and enforce) these requirements. Furthermore, issues of effective transfer of records when children move must be resolved. Ideally, each child has a medical record that follows him/her throughout childhood, so that at each new health care event all the relevant information is available to the primary care provider. Mechanisms to implement such a record are still in their developmental stages. Some promising approaches include the development of health diaries which are kept by patients themselves, with copies retained by their physicians.

Comprehensive Care

Concept: A primary care provider should provide a comprehensive array of needed personal health services for all but the most uncommon problems in the population. In addition to standard prevention, diagnostic, and therapeutic services for health problems, these services include clinical/technical interventions and related auxiliary services; human support that ranges from managing most psychosocial problems to helping children, adolescents, and their families cope with life's exigencies; patient and family health education; and facilitative services (i.e., services that enable the delivery of all other services, such as needed transportation, translation, day care, and eligibility services for public programs).

The specific set of services should be tailored to the needs of the population served as not all populations will have the same health care needs. A health need that is prevalent in one population (e.g., an immigrant population) may not be prevalent in others. Children with special health care needs related to chronic illness or disability, in particular, require a broad array of medical and health-related care as well as social/ family support services. Guidance for defining the content of child health services includes the Guideline for Health Supervision published by the American Academy of Pediatrics (AAP); The Report of the Select Panel for the Promotion of Child Health, Better Health for Our Children: A National Strategy (1981); and guidelines established by and for each state under its Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT) supported by Title XIX of the Social Security Act (Medicaid) in collaboration with the Title V Maternal and Child Health Agency. A generic list of clinical/technical and auxiliary services can be found in Section 330(a) of the Public Health Act and related regulations, and in Bright Futures: National Guidelines for Health Supervision of Infants, Children, and Adolescents (in press). Unfortunately, these documents are not in agreement as to the basic set of benefits or even the categories in which they fit.

In the case of needs that cannot be met by the primary care provider because they are too uncommon for that provider to maintain competence, it is the primary care provider's responsibility to refer the patient to another provider/facility where the service(s) can be obtained. Primary care providers must therefore be well informed about other providers and services in the community. The primary care provider must also ensure that the patient obtains the needed services and, when needed, facilitate the process.

Evidence of Benefits: The literature documenting the benefit(s) of comprehensive primary care is sparse (Starfield, 1992, pp. 58-63). There is also disagreement on the extent to which primary care itself should assume responsibility for certain preventive activities that might be better done in the public health sphere (Silver, 1978; Starfield and Vivier, 1993).

Discussion: There is little empirical evidence of the benefit of comprehensiveness, and no consensus regarding the list of services that constitutes comprehensive care. Furthermore, different health insurance policies cover different sets of services. There is little doubt that the lack of health insurance coverage poses a problem in accessing service (see Butler et al., 1985), but even among those children with coverage, gaps in the types of services covered exist. While most medical/technical services for illness care are covered by health insurance, preventive services often are not. Furthermore, facilitative services and counseling services are almost never covered. Until health care reform is enacted and implemented, this will continue to pose a problem.

Given the varying health care needs of different populations, it is impossible to define a set of services that will meet the needs of all populations. However, not defining a minimum set of services that must be provided (or referred out) is likely to prolong the current situation in which a number of important services (e.g., preventive and facilitative services) frequently are not provided, thereby endangering the health of children and adolescents in this country. Public health agencies may have an important role to play in measuring the health needs of different communities and in assuring that the health services provided are designed to address the full range of those needs.

Community-Oriented Care

Concept: Although primary care is personal health care, it must be delivered in the context of the community. The distinguishing feature of community-oriented primary care (COPC) is that it takes into account the health care needs of a defined population. Community-oriented care therefore is concerned with the health care needs not only of children and adolescents being seen by the provider, but also with those children in the community whose health care needs are not being met. If certain subgroups of children or adolescents are not currently receiving primary care services, the primary care provider should initiate corrective action to remedy this situation, for example, through outreach programs.

Delivery of primary care services is based on an understanding of community needs and the integration of a population perspective into clinical practice. Primary care providers are responsible for supporting public health roles and activities through epidemiologic awareness and reporting of specific health problems identified in the course of delivering personal health care services. In addition, primary care providers should contribute to and participate in collecting information to characterize the health needs of communities, health surveillance, and monitoring and evaluation activities that are routinely conducted by public health agencies. The public health sector, in turn, should be responsible to primary care providers and provide them with data that are necessary to plan and evaluate services. Community-oriented care assures that the views of community members are incorporated into decisions involving policies, priorities, and plans related to the delivery of primary care.

Evidence of Benefits: While there exists a relatively large literature defining the concept of and approaches to community-oriented primary care (for example see Mullan and Kalter, 1988), only a small number of studies have documented specific benefits from community-oriented primary care for children and adolescents, and many of them are from developing countries.

Kark and Abramson (1992) report that epidemiological evidence has been successfully incorporated into primary care practice in Israel, with resulting reductions in the prevalence of hypertension, hypercholesterolemia, cigarette smoking by men, and obesity. DeVries and Sparks (1989) report that in Columbia, South America, a comprehensive approach to health services is more effective than a narrowly focused approach; and that a health services project must be requested by, led by, and owned by the community to be successful. In the U.S., Porter and Butler (1987), in a study of five community-based health care programs, find that well-planned and universally accessible health care is intimately linked with both cost and quality, with access to care positively related to quality and negatively related to cost. Koska (1990) reports the success of increasing access to and

continuity of care in Texas, noting the advantages of being able to set up bonuses for the providers when community-based health targets are reached or exceeded.

Rosenbaum (1987) cites improved health outcomes (e.g., major reductions in infant mortality, declines in rheumatic fever) for communities served by community and migrant health centers. Similar benefits are cited by Nutting, Wood, and Conner (1985) for communities served by the Indian Health Service and Kaiser-Permanente. Finally, Nutting (1987) confirms the importance of using population-based indicators when evaluating primary care program impact.

Discussion: Community-oriented primary care is especially important for children and adolescents, both because they are particularly affected by certain health hazards in the community (e.g., lead poisoning), and because they have the least ability to make their health care needs known and acted upon. While the primary care provider is most concerned with the needs of individual patients, the practice of primary care must occur with an epidemiological awareness and knowledge about the context in which illness occurs and can be prevented.

While the concept of COPC is theoretically appealing, it is not without problems. COPC currently offers little prestige and financial reward, in part because many COPC-related activities are not reimbursed (Rogers, 1982). Perhaps as a result, there is little physician interest in COPC (O'Connor, 1989), making it difficult to implement even where mandated.

An additional problem faced by most practicing physicians is a lack of technical skills and financial resources needed to obtain information on community-based health needs, although this problem is not insurmountable (Frame, 1989). These problems aside, the mere definition of an appropriate community is for many primary care physicians a concept that would be very difficult to operationalize and implement on their own (O'Connor, 1989).

Public health agencies have an important role to play in sensitizing practitioners to the importance of a community orientation as well as to help them in incorporating its principles in their own practices. They can provide information about various manifestations of inadequate care (Starfield, 1992, pp. 192-5) as well as information on environmental factors that have to be taken into account in order to understand the genesis of health problems or to interfere with their prevention and management. They also can design and implement systems of monitoring in order to help health services providers assess the extent to which their services are helping to reduce morbidity and promote health.

Family-Centered Care

Concept: Family-centered care recognizes that the family is the major participant in the assessment and treatment of a child or adolescent. As such, families have the right and responsibility to participate individually and collectively in determining and satisfying the health care needs of their children and dependent adolescents. Being family-centered means that policies regarding access, availability, and flexibility take into consideration the various structures and functions of families in the community being served. Family-centered care reflects an understanding of the nature, role, and impact of a child's health, illness, disability, or injury on the family and the impact of family structure, function, and dynamics on both risks to ill health and promotion of health.

Children's health care needs cannot be identified in the absence of the family. Children are exposed to environmental health hazards as a result of their family's social and economic circumstances, and lifestyle; they are vulnerable to particular diseases because of their genetic predisposition; and they may suffer physical health consequences of family stress such as divorce, unemployment, and parental disability. Furthermore, because children generally are not in a position to seek health care on their own, even when illness symptoms are present, the decision to seek health care is a family matter. A primary care provider must therefore understand not only the physical health risks of a child but also family stress as well as the various social, economic, psychological, emotional, and cultural factors that influence a family's decisions to seek health care for a child. Finally, because compliance with a prescribed treatment for children is likely to be influenced by their family, family impact must also be considered when deciding on a child's plan of care.

Evidence of Benefits: While few have compared the effect of family-centered primary care as distinguished from primary care focused on individuals, a number of studies have confirmed the impact of the family (in particular the mother) in health care seeking behavior.[7] Karofsky et al. (1991) find evidence of decreased problem visits and increased health supervision in a pediatric practice among children whose initial visit included a family interview with all family members. Rogers (1981) finds that family-centered behavioral interventions are more likely to successfully prevent accidental poisonings, and that a mother's poor emotional status is associated with repeat poisonings. Crockett (1987) reports that family-based interventions are useful for reaching high-risk school-age populations when promoting healthy behaviors; and San Agustin et al. (1981) find that teams of internists and pediatricians achieved better results than pediatricians alone in keeping older children in their practices as they grew older (longitudinality), providing more timely immunizations and fewer visits overall. Picken and Ireland (1969) find evidence of family patterns of utilization in a Scottish population; they concluded that medical care utilization depends both on the distribution of illness and the distribution of patterns of illness behavior among family members. In a later study, Schor et al. (1987) conclude that families establish patterns of health behaviors that are stable over time and therefore may be amenable to selective interventions.

Discussion: While there is ample evidence supporting the importance of providing family-centered care, providing such care is not easily implemented. Evidence suggests that while family practice physicians support the concept of family-centered care, not everyone has either treated other family members or known much, if anything, about the structure or functioning of their patients' families (Pless, 1984). Furthermore, family practice residency programs vary greatly in their focus on and opportunity to treat all family members. The likelihood of family-oriented training in pediatric or

internal medicine educational programs is even less. Thus, before family-centered care can be implemented, it is necessary not only to educate providers concerning the importance of family-centered care, but also to provide the necessary training to enable providers to incorporate families into their treatment of children and adolescents.

There are several other components of primary care that are important, although they may be equally important in other levels of care (emergency care; consultation care; referral care) as well. These include accessibility of care, cultural appropriateness of care, care that is appropriate to the developmental stage of the individual, and care that is accountable to those who receive it..

Accessible Care

Concept: Accessible care facilitates the entry into care when it is needed. While it is a key component of first contact care (Starfield, 1992) in so far as first contact care must be accessible, it is included here to emphasize its importance.

Access is a multidimensional concept. It may be divided into different components such as: availability, geographic accessibility, accommodation, affordability, and acceptability. Availability refers to the adequacy of the supply of providers relative to the demand for services. Geographic accessibility refers to the physical location of the provider in relation to the location of clients, taking into consideration client transportation resources and travel time, distance and cost. Accommodation refers to the way in which the health care services are organized to accept clients (e.g., appointment systems, hours of operation, telephone services). Affordability addresses the relationship of prices of services to clients' ability to pay, given their health insurance status. Acceptability is the relationship of clients' attitudes about personal and practice characteristics of providers to the actual characteristics of existing providers. Acceptability also refers to provider attitudes about acceptable personal characteristics of clients (Penchansky and Thomas, 1981. See also Starfield, 1992).

While each of these subdomains of access to care must be addressed by primary care, not all of these domains are equally the responsibility of the primary care provider. For example, evidence suggests that access to primary care is impeded when co-payments and/or deductibles are a feature of health insurance. Primary care providers can facilitate affordability only to the extent that the overall health system assures that everyone in the population receives needed care even if unable to pay for it individually.

Evidence of Benefits: A large number of studies have documented the benefit of facilitating access to care in general on morbidity and mortality (see Starfield, 1985, for a review). Few studies, however, investigate the separate impact of its various components. In general, studies find that while access to care for poor children improves when public policy is directed at achieving this goal (Andersen, 1978), poor children still have inadequate access to care given their greater health needs

(Newacheck, 1988; Butler et al., 1985). Access to care is better for poor children on Medicaid as compared with poor children without Medicaid, but Medicaid coverage does not ensure access to care similar to other children in terms of locations and continuity (St. Peter et al., 1992).

Among several possible reasons for lacking a regular source of ambulatory care, affordability problems are most commonly cited, followed by geographic accessibility, and acceptability problems (Hayward et al., 1991).

Discussion: Current health care reform efforts focus primarily on affordability, but access to care for **all** children and adolescents, as mandated by OBRA '89, cannot be achieved without consideration of additional services and supports needed to assure appropriate use and effectiveness. For example, public health agencies can improve the acceptability of services through comprehensive community based assessments that seek to understand the priority health care needs of the population served, as well as their satisfaction with care. These agencies can improve the availability of services by taking a lead role in the development of policies that assure an appropriate distribution and mix of providers. Public health programs' special outreach activities to draw high risk and vulnerable populations into care are also important in the broader picture of accessibility. Health care reform efforts must be directed at improving all aspects of access.

Culturally Competent Care

Concept: Culturally competent care refers to care that honors and respects the beliefs, interpersonal styles, attitudes, and behaviors of clients (both children and their families) and the multicultural staff who are providing the services (Division of Children with Special Health Care Needs, 1992). It differs from "cultural sensitivity" in that the latter merely acknowledges cultural differences, whereas the former implies skills that help to translate beliefs, attitudes, and orientation into action and behavior (Roberts, 1990).

Culturally competent care incorporates cultural differences into the provision of health care by a number of activities including but not limited to: needs assessment to identify different cultural styles and emphases, and education regarding cultural diversity.

Services should be tailored to the particular cultural context of different groups of people in the community, who may be distinguished by their own shared values, different language, world view, heritage, and institutions, and different beliefs about the cause and meaning of health and disease. When these differences represent different socioeconomic backgrounds, this must be taken into account as well (Thompson & Thompson, 1990). A mechanism should be in place to represent the views of these different groups and incorporate them into decisions involving policies, priorities and plans to improve the delivery of services.

Evidence of Benefits: Because there are not yet instruments to assess the extent to which care is culturally competent, existing research has been devoted to defining and describing it (e.g., Heggenhougen, and Shore, 1986; Lynam, 1992; Roberts, 1990). Indirect evidence regarding the need for culturally competent care is found in studies that find different disease patterns, health beliefs or health-seeking behaviors across different cultures. For example, Hispanics--the fastest growing minority in the U.S.--are at increased risk for diabetes, hypertension, tuberculosis, HIV,

alcoholism, cirrhosis, certain types of cancer, and violent deaths (Council of Scientific Affairs, 1991). Horner, Lawler, and Hainer (1991) document that black patients of primary care physicians are almost three times more likely than white patients to die in-hospital following admission to an intensive care unit. Most of the differences were explained by variations in disease severity (Horner, Lawler, and Hainer, 1991), which might in part be related to poor care that has not addressed different cultural needs, as well as to social circumstances that heighten the risk of adverse effects in these populations.

Discussion: While the concept of providing culturally competent care is theoretically appealing, it is difficult to operationalize and, consequently, few studies have been published directly documenting its benefits. The challenge to providers and scholars of primary care is to develop the concept of cultural competence to the point where it can be implemented.

Developmentally Appropriate Care

Concept: Developmentally appropriate services integrate the developmental levels of children and adolescents into the assessment, prevention, and management of health conditions and into the design, location and policies that provide the context for the services being delivered.

Children undergo a number of significant changes from infancy to adulthood.[8] Their bodies change, their immune systems develop, they gain greater control over bodily functions, and they develop cognitive, emotional, and social skills. Each stage of development is associated with a different set of challenges. The primary care provider must therefore not only be familiar with the particular problems associated with a certain age (or stage), s/he must also know the preventive care needs of the age, as well as be able to screen for developmental delays or abnormalities. To meet this need, the American Academy of Pediatrics has developed periodicity guidelines for health supervision. These guidelines have specific recommendations for the number and content of health care visits by age throughout infancy, early and late childhood, and adolescence (Strain, 1984).

Evidence of Benefits: The literature in this area tends to focus on describing and defining what constitutes developmentally appropriate care (e.g., Strain, 1984), rather than evaluating its effectiveness. Indirect evidence suggests that this is an attribute of care that may deserve greater attention. Perrin and Perrin (1983), for example, find that physicians often do not know at what age to expect appropriate responses from children in response to questions about themselves, indicating a greater need for educating physicians about developmental stages and competencies of childhood.

Some studies have evaluated the impact of providing information to mothers regarding their children's development. Dworkin et al. (1987) find no impact of providing such information on a variety of outcome measures (e.g., maternal-infant interaction, maternal perceptions and attitudes), but Kelly, Sein, and McCarthy (1987) find that age-appropriate safety education that is repetitive and individualized and that requires parental participation results in improved parental knowledge of injury prevention and an improvement in certain safety procedures.

Discussion: There is a general professional consensus that primary care should be developmentally appropriate. Defining and measuring developmentally appropriate care is, however, a more complicated matter. The medical aspects of care are probably the least controversial but the preventive services are subject to greater debate. The AAP, along with the Maternal and Child Health Bureau and the Medicaid Bureau (Bright Futures: National Guidelines for Health Supervision of Infants, Children, and Adolescents, in press), is issuing guidelines concerning the timing and content of health supervision visits, but scientific evidence to support the specific number of visits or the particular content recommended is scarce (Wagner, Herdman, and Alberts, 1989). In this era of spiraling health care costs, care must be taken to avoid mandating health services that have little or no evidence of effectiveness from either strong theory or empirical studies, even if they are conceptually appealing. Therefore, recommendations or mandates regarding developmentally appropriate care should be accompanied by increased research to determine what truly constitutes effective developmentally appropriate health care services.

Accountable Care

Concept: Accountability is defined by Butler (1992) as "explainable" and "answerable." Conventionally, accountability has focused on the technical adequacy of specific clinical services provided (quality assurance). The concept of accountability is broader in that the primary care provider is accountable not only for the quality and appropriateness of clinical services, but also for ensuring that the attributes of primary care listed above are provided. Accountable care therefore establishes and monitors standards for each attribute of care. It also assures that services are delivered in accordance with current best professional practices.

Evidence of Benefits: It is beyond the scope of this paper to review the evidence concerning particular professional standards for clinical practice (which in many cases lack established scientific validity), and the literature on assessing primary care is only in its infancy. A few studies have attempted to develop indices to measure particular aspects of primary care but none have developed standards for assessing all the attributes of care. Hoekelman and Peters (1972) developed a health supervision index to measure standards of well-child care, but did not evaluate the usefulness of this index. An index of accessibility for ambulatory health services by Simon et al. (1979) suffers from the same shortcoming. Work is currently under way at the Child and Adolescent Health Policy Center at the Johns Hopkins University to develop assessment tools for all attributes of primary care (Cassady et al., 1992), however, these assessment tools must be validated before standards for individual attributes can be developed and subjected to assessment for adequacy.

Discussion: If primary care is to achieve its full potential as discussed above, the primary care provider should be accountable not only for the quality of clinical services provided but also for the implementation of all the attributes of care. While professional standards for clinical services have been developed by organizations such as the American Academy of Pediatrics, standards have yet to be developed for the way care is provided. It is increasingly recognized that, for care to be accountable, it must improve health status and do so in a way that is both acceptable to people and ethically and economically justifiable given societal standards.

An additional issue which must be resolved is how (and to whom) primary care providers will be held accountable. Currently, individual physicians are for the most part held accountable for professional standards of care by professional organizations and through certification (Benson, 1991). More recently, accountability has additionally been implemented through third party reimbursement/utilization review, including certification practices and processes of public programs paying for care (e.g., Medicaid, Title V, Title X, etc.). To achieve accountability, a mechanism should be developed to assure the implementation and continued enforcement of all the standards for primary care and monitored by agencies that represent the public trust.

CONCLUDING COMMENT

This document has described and discussed the ten essential attributes of care contained in the Maternal and Child Health Bureau's definition of primary care. While the research literature does not extensively address all these attributes, there is sufficient evidence to support the notion that the health of children in this country will greatly improve if every child has a primary care provider who provides care that achieves all ten attributes.

NOTES

1. This Center is funded by MCHB to help identify the national themes and policies that are critical to the successful implementation of the Title V amendments enacted in the Omnibus Budget Reconciliation Act of 1989 (OBRA '89).

2. The analysis of the benefits of first contact, continuous, and coordinated care have been extensively reviewed by Starfield (1992), and therefore are summarized only briefly in this paper.

3. This definition was formally adopted by the MCH Bureau in 1993, and published for broad dissemination within the MCH community in February, 1994.

4. The concept of "continuous" care conveys the same sense as the concept of "longitudinal" care employed by Starfield (1992). "Continuous" is used here because of its wider recognition despite the inconsistency in its meaning in the existing literature (Starfield, 1980).

5. The definition of "community" that is given in the Guidelines for the Title V Maternal and Child Health Block Grant Program (page 64, FY92) is:

> "A group of individuals living in proximity with one another linked conceptually for the purpose of defining and coping with problems or group of people linked, in fact, through interactions by common geographic and cultural identity."

6. The definition of "family" that is given in the Guidelines for the Title V Maternal and Child Health Block Grant Program (page 65-66, FY92) is:

> "A child [a person from birth through age 21] and the person(s) regularly interacting with him or her over an indefinite period of time."

This definition covers any structural configuration or living arrangement, and can include people who may or may not be related by birth, marriage, or adoption. It thus includes foster care arrangements, single parent households, "blended" families, and "extended" members who may not live in a given household, but who regularly interact over an indefinite period of time.

7. A number of studies also investigate the impact of a child's illness on family functioning (e.g., Kalman, 1980; Gayton et al., 1977; Fife, 1980. See also Schwenk and Hughes (1983) for a review), but these studies are outside the scope of this paper.

8. Breslow and Somers (1977) define 10 developmental stages during a person's lifetime for purposes of lifetime health monitoring. Five of these stages (pregnancy and perinatal period, infancy, preschool child, school child, adolescence, and young adulthood) take place before a person's 21 birthday.

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